Treatment of kidney patients

3977. SHRI RAJU PARMAR: Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) the estimated number of kidney patients in the country and the expenditure being incurred on the treatment of kidney patients annually by Government;

(b) whether the demand and supply of kidney has fuelled a prosperous kidney trade in the country by unauthorised persons violating Transplantation of Human Organs Act; and

(c) if so, the steps Government have taken or propose to take in this regard?

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SHRIMATI PANABAKA LAKSHMI): (a) The Government do not centrally maintain data about kidney patients and expenditure incurred on their treatment. Indian Council of Medical Research have informed that kidney diseases are not notifiable and data on prevalence of kidney diseases is not collected routinely in the country. Hence, exact number of End Stage kidney failure patients in the country is not clearly known. Clinicians estimate that 1 to 1.5 lakh such patients emerge annually out of whom only eight to ten thousand patients get treatment. Central Government employees who undergo such treatments at All India Institute of Medical Sciences, Government Hospitals or other Central Government recognized centres are reimbursed the expenditure incurred as per rules.

(b) Some cases of alleged illegal transplantation of kidneys have come to the notice of the Government of India. Sale and purchase of human organs is banned under the provisions of the Transplantation of Human Organs Act, 1994. The Act contains stringent provisions for punishing any one who commits such offences. Under Section 13 of the Transplantation of Human Organs Act, 1994, the Central and State Governments are empowered to appoint Appropriate Authorities for the purpose of the Act who are empowered to investigate any complaints of breach of provisions of the Act including those pertaining to sale and purchase of human organs. The Director General of Health Services is the Appropriate Authority appointed by the Central Government in respect of Union Territories. In respect of States, action under the Transplantation of Human Organs Act, 1994 has to be taken by the concerned Appropriate Authority.

(c) Government have constituted a Committee on the directions of the Hon'ble Delhi High Court (as per the judgement dated 6.9.2004 in W.P. No. 813/2004) to review the provisions of the Transplantation of Human Organs Act, 1994 and the Transplantation of Human Organs Rules, 1995. The composition of the Committee and terms of reference are given in the Statement (*See* below). The recommendations of the said Committee are awaited.

Statement

Composition of the Committee and terms of reference

The Composition of the Committee is as follows:—

1. Dr. S.Y. Quarishi, Addl. Secretary & DG, National AIDS Control Organisation (Nominee of Secretary (Health) and Convenor)
2. Prof. S.N. Mehta, Head of Department, Surgery Department, AIIMS—(Member)
3. Dr. Harsh Johri, Renal Surgeon, Sir Ganga Ram Hospital, Delhi—(Member)
4. Secretary, Indian Medical Association, I.P. Estate, New Delhi—(Member)
5. Mr. Sanjay Jain, Advocate, Chamber No. 488, New Chambers Block, Delhi High Court, New Delhi—(Member)
6. Dr. V.K. Arora, Addl. DG—(Member Secretary)

Terms Of Reference Of The Committee Constituted As Per The Judgement Dated September 6th, 2004 In W.p. No. 813/2004 Of High Court Of Delhi To Review The Provisions Of The Transplantation Of Human Organs Act, 1994 And The Transplantation Of Human Organs Rules, 1995

1. Based on the data available on the transplantation of organs and the working of the Authorisation Committees, the Committee to examine and make its recommendations on the composition of Authorisation Committees and changes, if any, required to ensure timely permissions.

2. Whether the jurisdiction of the Authorisation Committees should be enlarged by bringing within its ambit the process of certifying a "near relative" or the task be assigned to another designated authority?

3. Review the provisions of the Act and Rules based on the experience of transplantation of organs as carried out and the difficulties arising due to the bottlenecks faced in the said process. The Committee to examine in particular provisions of Section 9 and requirement of carrying out the tests prescribed in Rule 4, certification in Form-3 to review the definition of "near relative" and make its recommendations in the light of the observations made.

4. Examine and specify the organs for transplantation of which the tests prescribed in Rule 4(1)(c) to establish the factum of being "near relative" need not be carried out when other evidence is available.

5. Examine the feasibility of establishing and setting up Organ Procurement Organizations with data bank to facilitate the dissemination of information on availability of organs for transplantation to encourage organ donation especially from cadavers, cases of brain stem deaths and other deceased persons, who had authorized removal of organs upon demise.

6. Examine the feasibility of creation of a fund, the corpus to be provided partly come from the Union of India and partly by levying a fixed charge on the total bill of the hospital for transplantation and/or public donations, for providing social incentives to a donor.

7. Examine and recommend ways and means to give such incentives, including but not limited to help and aid any preferred health care, recognition and honour to a donor in the community.

8. Examine the causes that lead to exploitation of poor and unaware persons in the process of organ donation and suggest methods to reduce, control and ultimately eradicate such malpractices. Recommend programmes for dissemination of correct information of ethical, legal and devising procedure concerning organ donation so that a conducive atmosphere is generated and disinformation and misgivings are dispelled.

9. Any other matter relevant to the subject.